Consumer Advisory Group Meeting
November 18, 2013 12:30-2:00 P.M.

Name	Organization
In Person	
Kathleen Donaher	Regis College
Lisa Fenichel	eHealth Consumer Advocate
Amy Caron	EOHHS
Phone	
Winnie Tobin	Medically Induced Trauma Support Services
Alec Ziss	CapeCare
Support Staff	
Mark Belanger	Massachusetts eHealth Collaborative
Erich Schatzlein	Massachusetts eHealth Collaborative

Date	Physical Location	Dial In
22-Jan-14 10:00-11:30	In Person - MMS Middlesex Central Conference Room	Phone line open but in person attendance encouraged
26-Feb-14 10:00-11:30	Phone only	(866) 951-1151 x. 8234356

Review of Materials and Discussion:

The meeting focus and discussion was directed toward the Mass HIway Content for Consumers document distributed to the group along with the standard meeting materials. The group actively discussed, reacted to, and made suggestions on the content presented.

The meeting began with an introduction of Amy Caron, Project Manager of Mass HIway Communications for the Executive Office of Health and Human Services (EOHHS). Amy has been provided with the all consumer facing materials that have received input from the Consumer Advisory Group thus far. Her current goal is to make patient education and engagement materials available to consumer and providers in the near future.

Amy shared some background information on her personal healthcare experiences that drove her toward a passion in the healthcare industry. The group warmly welcomed Amy.

Content: The stock content discussed during the meeting can be used to develop content including a "one-pager" fact sheet, trifold, website content, frequently asked questions document, and presentations.

Synopsis of the group discussion of the content:

- The group suggested less of a "marketing approach" for the consumer content. Currently, the group believes the content includes only the positive side of the HIway and does not give ample representation of potential risks for consumers. The group suggests an approach that adequately includes potential benefits, risks, and costs associated with consumer involvement with the HIway.
- The group concurred that there is a need for a representative consumer population to test HIway collateral with. A test of the materials to a representative group would allow the HIway to learn from the consumer feedback and adjust focus based upon reactions. This could be accomplished with the front office teams of early Mass HIway participants.
- The content for consumers should also include some details on the information being shared via the HIway, and not just on the high-level idea of information sharing. The consumers should specifically understanding that the HIway would be utilized for sharing personal health information (PHI) and the privacy and security associated with the type of information being shared.
- There is general worry from the group that about having meaningful conversations with the patient and physicians with regard to the Mass HIway. The HIway needs collateral to support these conversations. Materials need to be available but there must also be an alternative way to educate patients.
- The group indicates there is a desire to use the patient education and engagement for the HIway as an opportunity to let consumers know more about the current state of how patient information is shared. Presenting the current state would provide an opportunity to present how the HIway represents a future possibility for information sharing. A consideration in this approach includes a caution for presenting the current state of information sharing in healthcare broadly. If the communication message reveals problems that have nothing to do with the HIway, , discontent with health information sharing could be miss-directed at the HIway.
- The group believes there is a strong need to educate the provider population about the HIway. The providers will ultimately be fielding inquiries from the consumer population and are an integral and trusted component of the education and engagement process.
- The group recommends keeping a focus toward direct patient education as well. The HIway is progressing with a focus on organization/provider enrollment, and then consumer must be included in the outreach and education efforts.

- Question: It seems as though EOHHS is focused on consumer education content, but what will be the approach for the engagement to educate the 6.5 million citizens of the Commonwealth? Informed consent to participate in the HIway means that patients must understand the consent through engagement and education. There is a need to provide engagement though local groups and cultural communities, in the form of both high-level and lower-level knowledge formats to reach the diverse community.

- o Answer: It is crucial to find these points of contact to engage consumers and educate them on the HIway. The goal can be to build partnerships with existing community programs and healthcare organizations to help engage and educate consumers. The first step in the process is to build a solid set of educational collateral. After solidifying the message, community engagement will be a important follow-up step.
- Comment: The content being reviewed has no distinction between marketing information and education information. There is no cost-benefit discussion. The information only addresses benefits of the HIway and does not explain any potential downside. The material is more of a "selling piece." There is an appreciation for the simplicity of the material, otherwise nobody will read it.
- Comment: The document seems to assume that providers are already connected to the HIway.
  - o Response: The current approach for the document is to serve organizations that have already signed up for the HIway. Those organizations have the need to obtain consent from the patient. The information would not be going out to other organizations or direct to consumers who are not at an organization participating on the HIway.
- Comment: The drive is to get patients to sign-up, period. Providers are likely not going to take time to explain the HIway to patients because of already existing time constraints. Perhaps the front desk staff would have the responsibility.
- Comment: Consent has become very broad, and contains less meaning. When first discussed, consent was envisioned as a per provider opt-in, not per organization, and had more meaning.
- Question: With regard to the Relationship Listing Service (RLS), how many providers have access to a record in a large organization?
  - o Answer: An audit is not tied to an entity, but is tied to user log-in credentials and the access log. The first step is to give access to the audit log for the patient to view activity. The next step is to make the audit log more proactive from the vendor side similar to what banks do when contacting a member to ask them, "Did you buy gas in South Carolina?" A notification could potentially be sent to the patient informing them that their relationship list was accessed or a medical record request was sent via the HIway.

Next Steps:

- EOHHS should make consumer content available in the field immediately.
- Feedback should be obtained from the initial content release, and improvement can be subsequently made.
- Action Step: Sanction/Remedy. If a patient finds an unauthorized individual has viewed/shared his or her record, there is a need to report to a body for sanctions.
- Reactions to be taken into account by phase 2 design team
- Meeting notes synthesized and provided back to Advisory Group for final comments
- Presentation materials and notes to be posted to EOHHS website
- Next Advisory Group Meeting – January 22, 2013
  - Phone only (866) 951-1151 x. 8234356
- HIT Council – scheduled for December 9, 3:30-5:00 One Ashburton Place, 21st Floor

HIT Council meeting schedule, presentations, and minutes may be found at
http://www.mass.gov/eohhs/gov/commissions-and-initiatives/masshiway/hit-council-meetings.html